

Public Health Data Standards Consortium Web-based Resource Center Work Group

July 30, 2002, 11:00 AM to 1:00 PM Eastern Daylight Time.

Workgroup Members

Chair:

Tom Doremus, Information and Communications Specialist
Public Health Foundation (PHF)

Other Members:

Suzie Burke-Bebbee, Health Informatics Specialist
Centers for Disease Control and Prevention (CDC)
National Center for Health Statistics (NCHS)

Marjorie Greenberg, Chief
Data Policy and Standards Staff
Centers for Disease Control and Prevention (CDC)
National Center for Health Statistics (NCHS)

Hetty Khan, Health Informatics Specialist
Centers for Disease Control and Prevention (CDC)
National Center for Health Statistics (NCHS)

Katherine Kvale, Ph.D., Epidemiologist
Wisconsin Public Health Data Steering Committee

Denise Love, Executive Director
National Association of Health Data Organizations (NAHDO)

Anno Orlova, Ph.D.,
Associate Professor
Johns Hopkins School of Public Health

Edwin Ted Pratt Jr., M.P.A.
Director, Liaison and Government Relations
National Association of Local Boards of Health

Michelle Williamson, Health Informatics Specialist
Centers for Disease Control and Prevention (CDC)
National Center for Health Statistics (NCHS)

Vivian Auld, Senior Specialist for Health Data Standards
National Library of Medicine

Bob Kambic, Professor of Health Informatics

Welcome any new members and brief introductions

The WRC WG introduced two new members: Vivian Auld from the National Library of Medicine, and Bob Kambic, from Johns Hopkins University School of Health. Vivian has been at the NLM for 9 years. During that time she has participated in web page development and with projects involving the main data bases and system. She has been working on health data standards and HIPAA code set issues. Part of her work has involved the NLM unified language system which involves vocabularies dealing with health issues. Her experiences will benefit this workgroup. Bob has been part of the Johns Hopkins University School of Health. Along with Anna, he has been involved with teaching health informatics in the university. The rest of the workgroup introduced themselves with a brief amount of biographical information.

Follow up to last meeting

Anna sent her power point slides to Tom who is completing his review. If any other WG members are interested in helping with the review of this material, please send an e-mail to Tom or Anna.

Discuss basic role tasks and selection of WRC WG members as "Project Leads" (assistant task facilitators that, with the NCHS team, help to manage the WRC construction)

Tom suggested that perhaps the term "project leads" is not appropriate because the NCHS staff are listed as the project managers or officers for CDC purposes. The term "workgroup leads" met with the approval of the WRC. There are some workgroup lead positions that are detailed on the contracts and there are some that are yet to be named, particularly on the second contract.

Discuss basic role tasks and selection of WRC WG members and solicitation of PHDSC members and non-members as "Content Experts" (assistant task facilitators that will provide direct verbal and written input, content-specific URLs, emailed reports, and paper materials that will serve as core resources for the tutorials and fact sheets, etc.)

Some of these basic roles and tasks have been written into the contract. The WRC needs to move into an assignment of roles. We are working on a time frame that requires engagement of the contractors by the first week in September. The first contract will encompass the time from the first week in September to the first week in June. If the PHDSC is successful in securing additional funding, the second contract will proceed to September of the following year. It is important, in this short time frame, to decide who will fill these leadership roles so we can be ready to engage the contractor with only one more conference call. Suzie and Michelle have put these roles and tasks together very concisely, but their work is a product of the workgroups' efforts the past year.

Suzie walked the WG through areas in the contract that detail where leadership roles need to be defined. She referenced Section 12, subtask 1.1 of the task order which regards preparing a list of appropriate experts. This list will include 5 experts from the WRC side as well as 5 from the Lewin side, for a total of 10. Although this contract has not been totally negotiated, Lewin does have a copy. NCHS is looking at an outside partner, not to be disclosed at this time, to assist in funding the second contract. Each contract is designed to stand alone. The difference is the content. The first contract establishes the web site, while the second contract enhances the first effort and creates more “bells and whistles”. If the second contract funding is not secured, then it could potentially be funded by the WRC another year.

Subtask 6.1 details the creation of six documents. Lewin will take the lead for documents one, two and three for content, while the WRC will take the lead for four, five and six. The WRC will add to the content and comment on the design of how it appears on the web. For those documents where the WRC has the lead, the responsibility is already in place for number five, and number six is currently housed at NAHDO but will be refined by a contractor and repackaged to put on this new website.

Suzie then referenced the second contract on page 9. For items one, two and three, the contractor takes a secondary role. In this instance, Suzie will take the lead for number two and number three has already been contracted out. For item number four, the contractor will take the lead with Kate, Anna, and students providing the information. There was some concern about Lewin taking the lead as WG members feel that the content would need significant work from the WG members. Without additional funding, some WG members do not have the time to devote to undertaking such a major project. WG members understand the time commitments and suggest that members decide how much time they can devote to this project and that the contractor and other WG members respect that commitment. Some WG members were familiar with the work of the Lewin group and felt that Lewin would do an excellent job of researching specific topics, gathering materials, and putting them together into a cohesive manner. The Consortium members would serve as consultants, editors of documents, and subject matter experts regarding the design of the web site. Since Lewin has been involved with the Consortium since its beginning in 1998, they have much of the background necessary to understand what is necessary. WG members are encouraged to check out the Lewin products on the consortium web site, particularly the Education WG project. Lewin also has its own web site which is very impressive. The WG also suggested that once the basic web shell has been constructed, the WRC might determine that specific projects need more content and find a way to fund more work or research in that specific area. With the establishment of the 501(c)3 corporation, more funding may be available to elaborate on areas where the need is greatest. This project was compared somewhat to the Medicaid HIPAA Compliance Concept Model (MHCCM). The initial shell was established and has gradually been filled in by states that have conducted projects toward HIPAA compliance. The MHCCM is now on its third or fourth version and is used by other parts of the health care industry besides Medicaid.

WRC members are asked to consider whether they would self select to serve as workgroup leads, content experts, or some other task. Tom will collect e-mails from WRC members and others so that we can prepare this list prior to completing our negotiations with Lewin. Members who identify other individuals who might fill these roles are asked to contact those individuals to determine their willingness to commit to this project before contacting Tom.

Part of the Lewin contract will also involve monthly conference calls. Some of these will deal with content issues, and others with design of the web site. Agendas produced ahead of time will help members decide if they need/want to participate in a particular call. The WRC may also choose to conduct meetings separate from those involving the contract. Some of those meetings may be either briefly before or after the scheduled contract call. Such meetings will allow the WRC to discuss any issues they may wish to keep separate from the contractor.

Tom discussed the fact that his year as chair of the WRC is completed and, for personal reasons, he needs to change his participation from that of chair. The position is open for anyone who would like to volunteer. Tom will continue to participate in the WRC, and will help as necessary, but will not continue under the title of chair. While much of the work of this contract may reduce the need for the chair to do so much individual work, the reality is that the activities of the contract may also increase the workload in the short term.

Discuss roles for other WRC WG members that are not serving in the above capacities and brainstorm on role tasks

There will be a number of roles for WRC members beyond leadership of various contract elements.

- ❑ Serve as experts or recommend experts to assist in the tasks identified.
- ❑ Identify other tasks that are necessary to assure that the web site is usable for those who need it.
- ❑ Complete a brief bio that addresses their skills related to the tasks at hand. This would be useful to the WRC work and to members in their own work.
- ❑ Serve as point person to “market” the existence of the web site to other members of the PHDSC and other national entities.
- ❑ Utilize specific skills in web design and to review web design suggestions before they are presented to the rest of the group
- ❑ Commit to “test” the web site to be sure that it functions and problems are identified. The web site will have a response button that will directly notify the contractor of problems needing attention.
- ❑ Develop projects, such as the web site testing that students can accomplish - Anna
- ❑ Encourage local health departments to look at a list of web site references for inclusion, content, format, etc – Kate
- ❑ Discuss local health department participation at a committee meeting in September – Kate

- ❑ Help people understand the value of standards, not just data – WRC members
- ❑ Construct a page relating to vocabulary definitions – Anna
- ❑ Provide access to best practice examples about how local policy makers can make use of data
- ❑ Review the Community Health Data Indicator information to determine how this data could be used to help counties link to other similar counties and use the data for policy making www.communityhealth.hrsa.gov
- ❑ Consider how HIPAA privacy may affect such county level sharing of data
- ❑ Other tasks as identified by the contractor or the WG as the project progresses

Self-select and recommend persons for the above roles

Members should review the above listed roles and determine if they have expertise they could share, if they can participate in some way, and how much time they can allocate to any task. Contact Tom with selections and time availability on a monthly basis. Get concurrence from any individuals outside of the WG before recommending them.

Discuss next steps for each role category, to include solicitation of assistance external to WRC WG members for the above roles.

These will be discussed in more detail on the next call and as the project continues.

Discuss long-term strategy for funding the WRC (for further WRC content/tool additions and maintenance 'post-contract').

Once we have obtained non-profit status, we should start bringing in funding which can then be used to contract with people who are the core of public health informatics.

Adjourn

Action items

- ❑ Contact Tom or Anna if you are interested in reviewing her presentation material
- ❑ Review Lewin products on the NCHS and Lewin websites and bring comments to the next meeting.
- ❑ E-mail Tom with any tasks you are willing to serve as workgroup leader
- ❑ Volunteer or solicit volunteers for WRC chair position
- ❑ Review other roles to determine participation – self select to Tom or NCHS
- ❑ Obtain concurrence from other individuals who might serve as workgroup leader or fill other roles and notify Tom or NCHS of those suggestions.
- ❑ Complete a brief bio which focuses on skills relevant to this project – send to Tom
- ❑ Determine the hours per month you can devote to this project and send to Tom